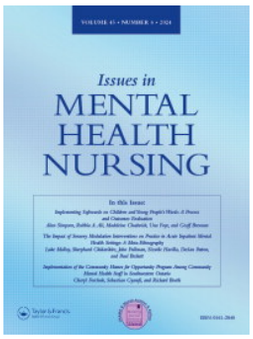

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Being Human Under Inhuman Conditions: Meanings of Living with Severe Dissociative States Involving the Experience of Being in Parts

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ABSTRACT

Severe dissociative states involving the experience of being in parts, typically associated with diagnosis such as dissociative identity disorder and other specified dissociative disorders, continue to be a controversial and rarely studied area of research. However, because persons with severe dissociative states are at risk of being harmed instead of helped within psychiatric care, their experiences of living with such states warrant further examination, while innovative ways to include them in research remain necessary. Against that background, this study aimed to illuminate the meanings of living with severe dissociative states involving the experience of being in parts. This is a phenomenological hermeneutic study with data collected from three social media sources, one personal blog and two Instagram accounts, in February and March 2023. The results were illuminated in light of four themes; Striving to remain in the world, Balancing exposure and trust, Balancing belonging and loneliness and Owning oneselves. The interpretation of the themes suggests that living with severe dissociative states means being a human under inhuman conditions, striving for coherence and meaning in a world that is often unsupportive. This calls for a trauma-informed care to better support recovery for persons with severe dissociative states.

Introduction

Experiences of being in parts are related to the identity alteration that follows the dissociative symptoms of compartmentalisation, and are characteristic for severe dissociative states, especially dissociative identity disorder (DID). Severe dissociative states involving the experience of being in parts, such as DID, are a controversial, seldom studied area of research despite DID's status as a valid diagnosis related to severe childhood trauma. The dearth of research may relate to stigmatisation of severe dissociative states as well as to a lack of knowledge about the states (Dorahy et al., 2014). At the same time, the need for trauma-informed care, an approach to nursing that promotes person-centered care and recovery for persons who have experienced trauma, has been increasingly stressed in research on psychiatric care (Cleary & Hungerford, 2015; Isobel, 2015; Isobel & Edwards, 2016; Muskett, 2014; O'Dwyer et al., 2021; Reeves, 2015; Wilson et al., 2017), which emphasises importance of studies that take into account the needs and experiences of such a neglected population. In that light, this phenomenological hermeneutic study marks an innovative attempt to illuminate the meanings of living with severe dissociative states involving the experience of being in parts on the basis of descriptions collected from social media. Snyder (2021) argues that persons experiencing dissociation are at risk of being misunderstood and remaining undiagnosed for years. Consequently, this study employs the term 'severe dissociative states involving the experience of being in parts' instead of referring to specific diagnoses such as DID or other specified dissociative disorders, which include symptoms of compartmentalisation (cf. American Psychiatric Association, 2013). This approach allows persons who self-report experiencing severe dissociative states to have their voices heard, even if they have not been formally diagnosed with a dissociative disorder.

Background

The mental process of dissociation is the brain's strategy for survival when a person is at risk of being overwhelmed following exposure to trauma. Dissociation exists on a continuum, from common experiences of daydreaming to more severe forms that greatly affects daily life. DID is considered to be the most pervasive type of dissociation (Snyder, 2021) and experiences of severe childhood trauma are closely related to its development (Şar et al., 2017). Characteristic dissociative symptoms include depersonalisation, derealisation,

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amnesia, flashbacks and nightmares. Moreover, it is common for the affected person to experience mood lability and feelings of shame, guilt and worthlessness (Snyder, 2021). A particular dissociative symptom of DID and other specified dissociative disorders is compartmentalisation (American Psychiatric Association, 2013) which induces an inability to control actions and cognitive processes that are normally controllable (Holmes et al., 2005) and allows the person at risk of being overwhelmed by stress to switch between separate parts of their personality. A person with the experience of compartmentalisation, or "being in parts", may be unaware of the different parts of their personality, however, and how they have acted (McAllister, 2000). For the purpose of this article, the experience of compartmentalisation is described as "being in parts", which includes other formulations of the phenomenon, such as being split, being many and being multiple selves.

As a way of handling the unbearable experience of trauma, dissociation comes with feelings of losing control, for the different parts of the personality can be experienced as uncontrollable (Tomlinson & Baker, 2019). Although the expression of different parts of one's identity, all of which have different characteristics, varies from person to person, it generally serves as a means for coping with daily life and allowing the person to be unaware of one's painful reality (Parry et al., 2018; Tomlinson & Baker, 2019). The experiences of conflict between one's different parts, marked by incompatible thoughts, feelings and actions, can thus cause a sense of being in a battle of wills (Marais et al., 2023). Descriptions of experiences of severe dissociative states also mention being disconnected from oneself, which relates to amnesia and the presence of other parts of the personality (Parry et al., 2017, 2018; Tomlinson & Baker, 2019).

The prevalence of DID is approximately 1% in the general population and higher amongst persons in psychiatric care (Dorahy et al., 2014). Diagnosis of severe dissociative states, especially DID, remain controversial and typically confront stigmatisation (McAllister, 2000; Snyder & Keepers, 2023; Tomlinson & Baker, 2019). For the same reasons, persons experiencing such states are at risk of being misdiagnosed (McAllister, 2000; Snyder 2021; Tomlinson & Baker, 2019), not receiving appropriate treatment and being met with scepticism (Boyer et al., 2022; Parry et al., 2017; Snyder & Keepers, 2023; Tomlinson & Baker, 2019). Indeed, when admitted to psychiatric care, persons with severe dissociative states face multiple challenges that only escalate dissociation (Parry et al., 2017; 2018). They may confront a lack of understanding about their experiences and consequently feel that they are being judged and misunderstood which increases their vulnerability and suffering (Parry et al., 2017). Few studies have described experiences of severe dissociative states from an insider perspective (Parry et al., 2017, 2018; Tomlinson & Baker, 2019). It's argued that further exploration of persons' experiences is needed to form a better understanding of how to support persons with severe dissociative states (Parry et al., 2018).

Because severe dissociative states are associated with cognitive challenges such as amnesia and difficulties to control different parts of the personality (cf. Snyder, 2021; Tomlinson & Baker, 2019) and there might also be experiences of being disbelieved, which create challenges for participating in research (cf. Dorahy et al., 2014). As an alternative to traditional methods of research, Salzmann-Erikson and Eriksson (2023) and Smith et al. (2023), have highlighted that involving the use of social media, which have gained interest in recent years, can be relevant in nursing research as a way to access insights into nursing-related issues. Smith et al. (2023) have described how online communities provide a safe environment for persons with specific health issues and that social media can reach an otherwise difficult-to-reach population and provide large sets of data that are suitable for different sorts of analysis. Meanwhile, Salzmann-Erikson and Eriksson (2023) have added that traditional qualitative methods fail to recognise the impact of the internet and new ways of expression, communication and pluralism that come with it (Salzmann-Erikson & Eriksson, 2023). Thus, considering the challenges that persons with severe dissociative states face in participating in research coupled with the availability of rich, in-depth descriptions of persons' lived experiences, we chose to collect data for our phenomenological hermeneutic study using social media. To the best of our knowledge, no previous study has involved collecting data from social media and analysing such data with phenomenological hermeneutics as a means to illuminate the meanings of living with severe dissociative states involving the experience of being in parts.

Rationale

Studies have shown that persons with severe dissociative states involving the experience of being in parts indeed need support but are at risk of being harmed instead of helped within psychiatric care, due to the stigmatisation of and the lack of knowledge of such states. At the same time, research on severe dissociative states has been limited and few studies have examined the content of care and support for persons with the states or their lived experiences from an insider perspective. Severe dissociative states are associated with cognitive and emotional challenges such as amnesia and difficulties with controlling different parts of one's personality and may also entail experiences of being disbelieved, all of which pose challenges for persons with the states in participating in research. Nevertheless, to ensure safe, adequate support and improve psychiatric care for such a vulnerable, neglected population, it is crucial to increase the knowledge and understanding for their experiences in studies that take their perspective. To this end, new, innovative ways of including persons with severe dissociative states as participants in research and creating possibilities for them to share their experiences are needed.

Aim

The aim of this study was to illuminate the meanings of living with severe dissociative states involving the experience of being in parts.

Method

In this phenomenological hermeneutic study, textual data were collected from social media platforms and analysed

following a phenomenological hermeneutic approach, inspired by Lindseth and Norberg (2004, 2021).

Patient and public involvement

Data collection and materials (i.e. the choice of using social media and possible social media platforms) were planned together with a representative, with personal experiences of living with severe dissociative states, of a national non-governmental organisation for persons interested in severe dissociative states. The results were repeatedly discussed and validated with the representative. The full manuscript has been communicated with the representative.

Data collection

Purposive sampling was used because it enables researchers to distinguish which participants to include based on their specific characteristics or functions. In this study, we targeted social media users with personal experiences of living with severe dissociative states (cf. Higginbottom, 2004). The data were collected from social media using a passive approach as described by Franz et al. (2019), meaning that official information (i.e. all data on the platform are available without restrictions) was collected (Franz et al., 2019). Thus, no form of interaction, such including friend requests, requests to follow the accounts or requests for group membership, was made with the persons who produced or published the material in order to not exert influence on them. Sources were identified by searching for keywords on Facebook, Instagram, and Google Search in February 2023. These specific social media platforms were chosen for their potential to offer openly available, rich, and in-depth written descriptions of the lived experiences of severe dissociative states. Google Search facilitated the identification of relevant blogs.

Materials

Data consisted of written texts from three social media sources, collected between 27 February and 1 March 2023. These three sources were selected based on the richness and depth of the material. Data from the first source, a personal blog written by one physical person, consisted of texts published between 1 June 2018 and 21 May 2019. Data from the second source, an Instagram account including posts from two physical persons, consisted of texts published between 11 July 2022 and 28 February 2023. Last, data from the third source, a joint Instagram account with posts from 17 different accounts as well as anonymous accounts, consisted of texts published between 19 November 2021 and 1 March 2023. All posts in the sources were written by persons with personal experience of living with severe dissociative states but targeted a broader audience. That is, all sources made either an explicit or implicit effort to spread knowledge and understanding about severe dissociative states and/or to make connections with other persons with such states. Data collection from the first source included all material available, while data from the second and third sources were collected to fill 100 pages in Office Word. In total, the data collected amounted to 264 pages of text in Office Word (i.e. 108,360 words). The data from all the three sources were collected by copying the texts from each source (i.e. all material available from the first source and material to fill 100 pages in Office Word for the second and third source) and pasting it into three separate Word documents, one document for each source.

Analysis

According to Lindseth and Norberg (2004,2021), the phenomenological approach aims to illuminate the essence of meaning of a certain phenomenon and the hermeneutic part in the phenomenological hermeneutic method is the interpretation of the text by entering the hermeneutic circle. Interpretation within the hermeneutic circle means to move between the whole and the parts of the text, a dialectical process between understanding and explanation, and is performed by following the three methodological steps of naïve understanding, structural analysis and comprehensive understanding (Lindseth & Norberg, 2004, 2021). The first step was to form a naïve understanding of the text by reading it as a whole while striving to grasp meanings of living with severe dissociative states. In the second step, structural analysis, the text was divided into meaning units that were subsequently interpreted to represent various themes of the phenomenon of living with severe dissociative states. In all, 2460 meaning units were included in the structural analysis, which was performed in several steps of thematisation that resulted in four themes that were later validated by being compared with the naïve understanding. The third step, comprehensive understanding, involved summarising the themes and interpreting the meanings discovered in relation to the phenomenon and theory. The text was again read as a whole while reflecting the naïve understanding and the themes in relation to literature in order to revise, widen and deepen our understanding. Thus, the comprehensive understanding that was developed stemmed from the hermeneutic part of the analysis with interpretations of the meanings found in the text. The first author was responsible for the formal analysis, and all authors were involved in critical reflection on each step. Themes were developed and revised following joint discussion.

Ethical considerations

Persons with severe dissociative states have symptoms including cognitive and emotional challenges, (e.g. amnesia and difficulties with controlling different parts of their personality) and are considered to be vulnerable research subjects who need additional protection against exploitation (cf. Shamoo & Resnik, 2015). Those ethical challenges may discourage researchers from including persons with severe dissociative states in their research and, in turn, perpetuate the lack of knowledge in the area. However, by following a modified approach it is possible to include persons with

severe dissociative states research, as demonstrated in this study.

Using texts from social media as data requires the consideration of certain ethical issues, especially concerning consent and confidentiality (McKee, 2013). Using data from official social media, however, is considered to pose less of a challenge, because such texts presumably strive to reach a public audience (Townsend & Wallace, 2016). After careful consideration, we chose to forgo the collection of informed consent from the persons who published the texts as a means to avoid interfering and exerting influence on them. Collecting informed consent was not considered to be necessary or even desirable based on the persons' choice to publish their experiences and make them accessible to everyone and the assumption that they are thereby interested in sharing their experiences and aware that their material may be circulated. Further, there is a risk that specific groups, pages and accounts may be identifiable which would violate the assumed anonymity for the persons who have shared their experiences. Along similar lines, measures have also been taken to minimise that risk, including not publishing search terms and search strings in this article. At the same time, although Moreno et al. (2013) have advised authors to avoid publishing direct quotes because it risks the anonymity of the persons who published the material (Moreno et al., 2013), we decided, to publish direct quotes in this article given the sheer difficulties of identifying the sources since the quotes have been translated from the original language into English. The study was approved by the national Ethical Review Authority (id: 2022-05968-01).

Results

This section presents the naïve understanding, the structural analysis and the comprehensive understanding, illuminating the meanings of living with severe dissociative states involving the experience of being in parts. To best represent the experience of being in parts, the expression "oneselves" is used instead of "oneself".

Naïve understanding

In the first step of the analysis, forming a naïve understanding, we aimed to grasp the initial meanings of living with severe dissociative states. This is experienced as existing in parts and striving to form a unity, a fragmented whole. Inner communication and cooperation make it possible to form a plural approach to life and for the parts to fit together and connect with and help each other. When such inner communication and cooperation fail, chaos emerges that affects the whole plural system as some parts hurt or fall outside the system. Some parts carry strong emotions and memories of previous trauma and, in effect, protect the other parts when triggered. Uniting the plural life takes endurance and energy, fatigue is common and the sense of time is difficult to grasp. Although the memories are painful and intrusive, they remain difficult to trust and ask questions about one's truth where one's entire existence is cast in doubt. At times, the body is perceived to belong to someone else and to be both disconnected and in pain. The plural system struggles to meet the needs of every part, for though young parts need of love, safety, care and kindness, those needs are triggering for other parts who want to defend themselves.

Living a plural life means being challenged while navigating a world of singular lives where one's right to exist is questioned and violated. When the parts' expressions of pain are met with disbelief and distancing, abandonment ensues that threatens to further fragment the parts. Although loneliness can be one's own choice, there is at the same time a desire for belonging in such way that all parts can exist, even the defensive ones that hurt. Reconciling the plural life in relation to the world of singular lives also requires standing up for oneselves in order to protect oneselves. Overall, the parts can form a unified whole, such that the plural life can be lived through insight, strength and courage.

Structural analysis

The structural analysis, conducted following the development of the naïve understanding, resulted in four themes. First, the theme of striving to remain in the world encompasses the lived experiences of remaining in the world with trauma, dissociation and challenges in life. Second, the theme balancing exposure and trust highlights a complex, sometimes contradictory fight when navigating the world of singular lives. Third, the theme of balancing belonging and loneliness illuminates the longing as well as the fear of belonging while the fourth theme, owning oneselves, includes the lived experiences of various aspects of ownership, healing and integration. In what follows, the four themes are detailed with subthemes related to each (Table 1).

Striving to remain in the world

Striving to remain in the world is related to experiences of being threatened to be dragged out of this world. Such strive is about navigating the minefield of one's past, being shielded by fog and holding on when overwhelmed.

Navigating the minefield of one's past

Striving to remain in the world encompasses the experience of navigating the minefield of one's past, consisting of trauma and it's remains in an ongoing struggle experienced since childhood. The navigation can be accomplished by

Table 1. Themes and subthemes.

Theme	Subthemes
Striving to remain in the world	Navigating the mined ground of one's past
	Being shielded by fog
	Holding on when being overwhelmed
Balancing exposure and trust	Fighting exposure
	Daring to trust
Balancing belonging and loneliness	Grasping for belonging
	Being lonely
Owning oneselves	Becoming whole
	Owning one's story

normalising one's experiences and thereby enabling the belief that one is well because no other references to wellbeing exist. That accomplishment allows living an ordinary life despite feelings of being different and struggles to identify with others. A distorted image of the world can be envisioned, then placing blame on oneselves makes the world less dangerous to remain in. Nevertheless, challenges remain that threatens to drag one out of this world for one's traumatic past continues to be present when triggered into flashbacks and dissociation. In that way, handling triggers is an act of navigating the minefield under a constant threat of explosions. Certain situations, places and experiences of longing for comfort and support are especially triggering for they recall feelings of exposure. Others' invasions of one's personal space and boundaries seem life-threatening and can be heavily triggering experiences that challenge the strive to remain in the world.

> I have memories hidden in a mental catacomb. They can explode as flashbacks. The fragmentation takes place when there's too much stress. Then I sort of break into pieces and can no longer hold myself together. #3:1099

Being shielded by fog

The theme of striving to remain in the world is highlighted in the experiences of being shielded by a dissociative fog that threatens to drag oneselves into a disconnected space where the sense of time is difficult to grasp where moments, hours or even days are lost. The body shuts down, and as its functions become unavailable, the body becomes alienated. In that state, there are feelings of unreality and remaining present is difficult. Striving to remain in the world while shielded by fog is complex because dissociation, on the one hand, offers a safe place but, on the other, is frightening and frustrating as well. Some dissociative experiences even exceed words and thus bring an indescribable aspect of the dissociative fog to light.

> Dissociation feels like resting in time and at the same time losing all time. Confused but thankful. Would I have lived without that defense? No. It's a shell to escape to and crawl into when the words and actions from the surrounding hurt. Like a turtle. #3:778

Holding on when overwhelmed

Striving to remain in the world was also identified in experiences of holding on when overwhelmed with pain, fatigue and a lack of energy, which demands constantly balancing one's energy and prioritising certain activities over others. Striking a balance between work and rest is difficult and life gets lost in everyday chores. Meaningful activities are greatly desired but at once avoided for fear of becoming overwhelmed, while not having enough energy to participate in life as desired becomes a source of frustration and sorrow. Holding on when overwhelmed becomes a struggle when the challenges of living cause such despair that suicide seems to be the most viable means of resolution.

> I'm often scared of getting too tired, that it feels like something threatening that I have to try to avoid. It's good that I value recovery and my wellbeing. But it's not always going well. I get too careful at times, I don't dare to plan something on days off because I want them for resting at home, I don't think I can cope with work and my life otherwise. Which makes me missing out on good things. #3:530

When holding on to remain in the world, both recognising one's strengths and abilities and identifying strategies to counter the challenges and make oneselves feel better, are vital. For that reason, it is crucial to allow oneselves to feel valuable, worthy of self-compassion and able to meet one's needs. Although achieving that mindset can be daunting and take significant time and effort, it also results in a drive to take care of oneselves. Overall, holding on when overwhelmed means being capable of setting goals for oneselves, refusing to give up and clinging to a sense of hope as a way of remaining in the world.

> I realized that there still was a big problem for me – that very attempt to selfcare led to a strong resistance within me. I got angry and got repeated impulses to hurt myself if I tried to be self-caring. So we have carefully worked on practicing to be self-caring. #3:526

Balancing exposure and trust

The theme of balancing exposure and trust refers to a complex process with sometimes contradictory meanings. Its subthemes include fighting exposure and daring to trust.

Fighting exposure

Balancing exposure and trust is highlighted in experiences of trusting that psychiatric care will provide safety but are instead exposed to a painful process of needing to fight disbelief about one's plural existence. In that situation, parts of oneselves are treated as being unreal and are thus ignored, which cause feelings of being violated and severely threaten one's existence. In response, fighting exposure in order to obtain appropriate support entails the struggle of finding a way forward with caregivers who do not understand one's needs and sometimes react with fear. When not fitting into the health care system one can be forced to access various caregivers and, in the process, experience retraumatising rejections and abandonments, all of which cause feelings of powerlessness and a sense of being wrong. Fighting exposure is essential for survival after being admitted to psychiatric inpatient care, which especially exposes oneselves to further trauma with severe threats to one's existence and feelings of not wanting to live anymore.

> I wish that the shame wasn't mine to carry. Do you understand that it's what you did to me with your so called care that made me want to escape, to die so intensely? Everything that meant something to me in life was taken away from me. Instead I got a room with you. You called it care. You wanted to protect me from myself, but who protected me from you? I don't know why you thought that your treatment would make me want to live again? I didn't know how I could get away from the situation I was in. I wanted to die, I wanted to escape. What you did to me, what you made me feel. The isolation, shame and humiliation. #3:74

Exposure to a profound hopelessness occurs when one has to fight forced compliance and a loss of one's power and

abilities. In short, although one may be admitted to psychiatric inpatient care as an independent, resourceful person, one can easily emerge from care as a person who needs constant support. Fighting such exposure thus requires recouping one's power in relation to others who claim to have rights to invade and make definitions.

> As soon as I dared to challenge and take the power back, I did it with emphasis. Maybe it went a little quick some might think? From one day to the next I got rid of the trustee and shortly after I got rid of the social support/assistance and none of them were replaced with anything else than faith in myself and the freedom to decide for myself. That's the way I wanted it. I had fought for that freedom. I deserved it. #1:445

Daring to trust

The theme of balancing exposure and trust includes daring to trust others and deciding to trust healthcare professionals even though such contacts demand repeat exposure. Upon meeting a healthcare professional who is understanding, who respect all parts of oneselves and who remains a safe ally when things get difficult, trust can outweigh the risks of exposure and one dares to accept the safe haven being offered.

> Now that I get to experience how a safe attachment feels. How it feels to have someone on one's side. How it feels to be able to talk about what's difficult and twisting and turning with someone. To cry for a while with someone who is just there. Who feels calm and safe. And can say something that makes it a little better. #3:408

Balancing exposure and trust is also identified in relation to others in everyday life. In those instances, the balancing act involves daring to trust one's right to set boundaries and not merely adjust to others, which has been a means to fight for one's survival under inhuman conditions. Against that effort, others who question, violate or abuse those newly set boundaries become threats to one's very existence.

> I have an extraordinary ability to adjust to the need of others. If others are happy the risks decrease for me. Therefore, I have always adjusted, taken consideration and understood others. Not always because I have been especially good or empathetic, but out of pure self-preservation. #1:14

Balancing belonging and loneliness

The theme of balancing belonging and loneliness is related to experiences of yearning for belonging but at once fearing it such that loneliness, though painful, is acceptable. Its subthemes include experiences of grasping for belonging and being lonely.

Grasping for belonging

Balancing belonging and loneliness is identified in the complex struggle to exist as oneselves in relation to others. In that struggle, one grasps for belonging even though it may be unattainable, in a process challenged by one's vulnerabilities due to insecurities, difficulties with trusting others and feelings of being different. Grasping for belonging can be overwhelming to the extent that one feels that one would be better off on one's own. Balancing belonging and loneliness is thus identified as a matter of challenging oneselves and, despite the risk of being rejected, one grasps for belonging by reaching out to connect with others. Doing so requires being open about oneselves and daring to see that one has value in the world, which gives a sense of hope and meaning to life. Being able to belong in different genuine relationships afford feelings of joy, pride and meaning.

> But it doesn't feel that there's any meaning to life, in a pure existential way that is. I have tried to find my place but it feels like I don't belong, if anyone knows what I mean? What do I need to do to feel that I belong? What is it that I have to change with myself? #2:349

Being lonely

Balancing belonging and loneliness also involves all of the contradictions of being lonely. Although loneliness is desired and one's own choice, longing for something else persists and the loneliness feels unfair and painful. When trying to balance belonging and loneliness one may have actively sought for belonging but not found it and, in turn, come to accept being lonely.

> Had a fiancé once a long time ago that just ended in misery. Since then we haven't tried anymore. There has never been a greater wish for children either. And we are content as it is now, just living with us in the system. #3:59

Owning oneselves

Last, the theme of owning oneselves is highlighted in the important and liberating, but nevertheless threatening, process including the subthemes of becoming whole and owning one's story.

Becoming whole

One dimension of owning oneselves is related to the experiences of becoming whole in relation to internal contradictions. Discovering different parts that exist within the same body is chaotic and frightening. When different parts do not cooperate, parts act out independently in contradictory ways which is destructive and chaotic. When exploring parts of oneselves as a way to become whole, many different and contradictory needs come to light and reveal a complex system whose parts can be triggered by one another. Becoming whole is challenging when parts conflict and seek to punish each other, with feelings of hate and confusion. Becoming whole is also a long-term process, for some parts need time and meeting all of one's parts can be an unbearable experience. Discovering parts carrying trauma means experiencing painful memories brought into light in front of other parts that previously have been protected from them. As the parts are forced to engage with one's history, feelings of despair can result.

> A lot of my self harm was about doing away little parts' needs that both grown up me and other parts perceived as repulsive and difficult to handle. Other parts perceived it as these little

> parts' needs caused chaos and destruction. The needs that were evoked felt so wrong and shameful that they just had to go. Some parts within me basically tried to kill others, so that the disgusting needs would go away. #3:1063

Becoming whole also involves healing and integration with various and sometimes contradictory meanings, such that it becomes important to own one's definition of becoming whole. One means of healing and integration is parts blending together, thus one is no longer being able to define the different parts. Healing and integration can also mean for the parts to coexist and be coconscious, and that all parts are essential to the whole. When being coconscious, every part's needs have to be respected and there's a desire to form the parts into a functional team that allows one to meet one's needs. Becoming whole in that way requires acknowledging every part's right to exist, appreciating each part as being valuable and understanding how they contribute to managing one's life in different ways. When living in a state of integration there is a sense of control and being whole with a reduction in chaos and amnesia and a liberating feeling of not needing to be scared. There is also a sense of having parts instead of being parts and a recognition of the different parts even though they no longer act independently without consent. Becoming whole means taking care of each other within, to understanding demanding expressions from younger parts who are scared and allowing other parts to comfort them even though it can be painful and traumatic. Becoming whole by being coconscious and retaining parts requires reconciling internal contradictions and at once developing a sense of togetherness, whereas becoming whole by not having parts is a relief but also a source of loneliness.

> I guess it's normal to sort of have a caring part of oneself, but for me it's like traces of my different parts, an adult part that comfort and take care of the child parts. It doesn't matter what the inner structure looks like, whether I'm still fragmented in some ways or if I'm whole and able to take care of myself. I think it feels good and unlonely to think of it as different parts of me. #3:744

Owning one's story

Another aspect of owning oneselves is related to owning one's story which is achieved by facing one's self-doubt, feelings of being unworthy and the sense that one is a sham who is faking one's past and present situations. Owning one's story entails articulating experiences, calling them by their names such as abuse and violation, without diminishing what happened, refusing to continue defending perpetrators and instead being on one's own ally. Owning one's story also entails revisiting trauma-triggering situations and replacing traumatic memories with a sense of control.

> A couple of weeks ago I went by my own childhood surroundings and realized that much have happened during those 25 years since I was there. Some of the houses are gone. Many of the persons that made me jump as a child and still make me jump rest on the cemetery. Some are alive, but old now. The house got a new façade and the balcony is gone. I'm completely calm walking there and I don't feel scared. I however feel that I don't belong there anymore. That what was no longer is. I survived and it's time to go home. #1:176

Owning one's story is an act of healing, and this ownership involves acceptance and self-forgiveness. At the same time, acceptance cannot be forced, nor should it require to forgive others for what is unforgivable or surrendering to unacceptable circumstances. In those cases, acceptance is not healing but diminishing. However, acceptance should be a process of placing shame and guilt where they belong. Self-forgiveness means to forgive oneselves for not being more resistant against violations and instead valuing one's ability to do what is needed to survive.

> When I accept (whenever I succeed but let's see it as a strive OK), then I see what happened to me just as it is and let it be like that. I can't change it. Then it's easier to put the blame where it belongs. And not on me. Understand why things happen within me now and how they shaped me and my behaviors, and what I need to do now to live as well as possible. All this instead of being angry with myself, hurting myself, feeling even worse and becoming more stuck in reactions related to memories, alarms and threats of shame and so on. #3:499

Comprehensive understanding

The comprehensive understanding consists of a last step of interpretation with reflections on the sense of the naïve understanding, the results of the structural analysis and relevant literature, all to illuminate the meanings of living with severe dissociative states involving the experience of being in parts (cf. Lindseth & Norberg, 2004, 2021). When the previous steps of the analysis were interpreted in depth in relation to each other and theory an overarching theme emerged; being human under inhuman conditions.

The meanings of being a human under inhuman conditions were emphasised throughout the naïve understanding and the structural analysis. The themes, *Striving to remain in the world, Balancing exposure and trust, Balancing belonging and loneliness* and *Owning oneselves* illuminate how one is a human, with human needs and desires who exists under inhuman conditions marked by trauma and exposure. In that state, meanings of life are complicated by numerous contradictions, both in relation to others and in relation to oneselves, that demand to be reconciled. One is constantly challenged to balance desires and threats to one's plural life. Because such life is handled with strength and courage and by forming a plural system for surviving and living in a world that often fails to be supportive, being human under inhuman conditions can be interpreted as a struggle for coherence in which the aspect meaning is especially essential. Through hope and courage, the person is able to cling to a sense of meaning that makes survival and living under inhuman conditions possible.

Being human under inhuman conditions entails the struggle of not giving up and continuing to search for understanding, belonging and ways of coping when challenged from both outside and within. In this study, that struggle is interpreted within the framework of a sense of coherence described by Antonovsky (2005) with special

emphasis on the aspect of meaning described by Frankl (2006). Being human under inhuman conditions means striving for comprehensibility, manageability and meaningfulness as described by Antonovsky (2005) in a constant search to understand oneselves, one's story and the world. It also involves the ceaseless work of finding ways to handle oneselves and one's experiences as well as finding meaning in an existence that is difficult to live within. Such work is required no matter how chaotic and difficult one's existence is, and, according to Antonovsky (2005), the search in itself is a sign of the person's belief that there is meaning in life. The component of meaning is not only cognitive but also emotional and is seen as the motivating component within sense of coherence. Meaning plays a central role in sense of coherence as a person with a low sense of comprehensibility and manageability can still demonstrate remarkable courage and engagement in searching for understanding and coping if the sense of meaning is present. Meaning in the context of sense of coherence is related to Frankl's descriptions of meaning (Antonovsky, 2005). Frankl (2006) illuminates the courage needed to suffer and to find meaning in it without diminishing one's reality (Frankl, 2006) and such courage is necessary when being human under inhuman conditions, daring to meet one's various parts and thus one's traumatic history, daring to stay in the reality of the world without normalising or distorting it and remaining in it when one is lured away by dissociation or other painful challenges of life. According to Frankl (2006), carrying one's suffering in that way allows creating meaning even in the most difficult situations in a process in which hope and courage are keystones (Frankl, 2006). Being human under inhuman conditions also means finding ways of being courageous in the sense of daring to be oneselves, standing up for oneselves and fighting exposure, all of which can afford feelings of hope. Moreover, Frankl (2006) describes how meaning in life does not need to be abstract but instead concerns having a mission that makes one irreplaceable (Frankl, 2006) and being human under inhuman conditions means to find one's mission through connecting and giving something valuable to the world, for example by sharing one's story in order to help others and make the world a better place, and by finding relationships in which one feels needed. Frankl (2006) also suggests that a desperate search for meaning is something that the person needs support and guidance through and not necessarily medication (Frankl, 2006) but in that case, psychiatric care has proven to contribute to inhuman conditions by exacerbating a sense of meaninglessness and incoherence instead of getting support. However, even though contact with psychiatric care are highly problematic it can also offer a safe haven that promotes a sense of coherence when the person is met with understanding and respect and gets support with coping with life.

Discussion

The meanings of being human under inhuman conditions is also illuminated in psychiatric care when one hopes to have one's human needs of safety and trust met but instead confronts inhuman treatments that cause further trauma and threaten one's existence. That finding aligns with previous research showing how psychiatric care can be retraumatising instead of helpful for persons with histories of trauma (Ashmore et al., 2015; Hennessy et al., 2023) when those histories are neglected and not taken into consideration (Hennessy et al., 2023). This calls for trauma-informed care which is considered to be a leading model for improving nursing in psychiatric care for persons with histories of trauma (Cleary & Hungerford, 2015; Isobel, 2015; Isobel & Edwards, 2016; Muskett, 2014; O'Dwyer et al., 2021; Reeves, 2015; Wilson et al., 2017). Trauma-informed care can prevent retraumatisation by focusing on safety, trust, relationships, environment and recovery (Isobel, 2015; Wilson et al., 2017). Personal recovery includes the aspect meaning and can be supported by creating meaning in one's experiences (Slade et al., 2014). Trauma-informed care is thereby a model to prevent inhuman conditions and support a recovery-oriented, human means of care.

Being human under inhuman conditions means finding strength and pursuing personal development as a way of living with one's experiences. In that state, owning oneselves in terms of owning one's story is important, as is being open with others. Acceptance and self-forgiveness are challenging but important when focusing on placing shame and guilt where they belong. That process can be understood as post-traumatic growth as described by Tedeschi and Moore (2021) and Bryngeirsdottir and Halldorsdottir (2022), in which unexpected strengths can be discovered while being forced to cope with traumatic experiences. However, because narrating one's story may cause feelings of regrets and guilt when acceptance is needed instead, openness can be a way of overcoming self-stigma and feelings of being an outsider such that the trauma is not the final chapter of one's story. In that process of growth, it's crucial for others to resist thinking that something wrong with the person and to focus on what happened to the person instead (Tedeschi & Moore, 2021). Moreover, post-traumatic growth should be met as a journey, not a destination and as necessarily including a recovery process. On that journey, willpower and courage are essential for growth to occur (Bryngeirsdottir and Halldorsdottir, 2022). For nurses, supporting post traumatic growth in psychiatric care presupposes a trauma informed approach to care (cf. Muskett, 2014; Wilson et al., 2017).

Strengths and limitations

Data were collected from anonymous accounts on social media. By using texts from social media it was possible to gather views from different parts of the personality that are able to share their experiences in writing. By contrast, in interviews, only one part of the personality may be present. Even so, our passive approach had limitations. Without engaging in interactions with the persons who published the material, we could not ask questions for clarifications or explanations. Furthermore, we could not gather any

information about characteristics, including age, gender, ethnicity or socioeconomic status. In this aspect, anonymity is a limitation for this study since we are not able to determine if the data represent a variation in age, gender, ethnicity and socioeconomic status, and thus could not identify any variation in those characteristics in the sample. At the same time, when living with severe dissociative states, it is possible to have a personality with parts whose characteristics do not align with the person's physical body. Thus, such information would be difficult to collect and, in any case, may be irrelevant. Beyond that, the sample was limited to persons who are willing and able to express their experiences in writing online, which necessarily excluded persons with a limited ability to express themselves in writing or limited access to the technology needed for posting on social media. Even with that limitation, the data collected were extensive and amounted to 2,460 meaning units, and although they thus provided richness and depth, it remains unknown how much material is ideal or even manageable in such an analysis. To ensure a credible analysis the process was systematic; the steps of the analysis were documented and the preliminary results were presented and discussed continuously throughout the process. Our understanding is that the selected sources offer rich and in-depth descriptions, making them suitable for phenomenological hermeneutic analysis to illuminate the meanings of living with severe dissociative states. Presumably, the persons who have chosen to share their experiences of severe dissociative states on social media have developed the ability to articulate their experiences in a clear and nuanced manner.

Regarding our use of social media, Salzmann-Erikson and Hiçdurmaz (2017) have argued that persons with experiences of trauma use social media as a way to reveal themselves, to get support from others in the same situation and to stand up against stigma (Salzmann-Erikson & Hiçdurmaz, 2017). However, social media can also be used as an advocacy strategy to raise awareness and support policy initiatives (Smith-Frigorio, 2020) which needs to be taken into consideration when assessing the transferability of the results from this study.

Last, in all, using a phenomenological hermeneutic approach, multiple possible interpretations of the given text are possible (Ricoeur, 1976). The results presented in this article are what we considered to be the most credible understandings of the data. On that count, the results were repeatedly discussed and validated with all authors as well as a representative of a non-governmental organisation with personal experience of living severe dissociative states.

Conclusions and clinical implications

This study on the experiences of living with severe dissociative states involving the experience of being in parts adds to a growing body of knowledge that highlights the importance of understanding the lived experiences of a stigmatised group that at great risk of being harmed in psychiatric care. Our contribution thus expands the knowledge base on how to support persons with severe dissociative states. Analysing texts from social media afforded an opportunity for different parts of the personality to have their voices heard. Living with severe dissociative states means being a human under inhuman conditions, struggling for coherence in a world that often fails to be supportive. Surviving and living is possible through strength and courage, which in turn facilitates a sense of meaning. Although there is potential to get support from psychiatric care, doing so is challenging for persons with severe dissociative states who are usually exposed and violated when seeking care. Those experiences of retraumatisation call for trauma-informed, recovery-oriented care that promotes trust and safety, as well as cultivates the strength and courage to create further meaning and coherence in life. Additional research is needed, however, to better understand how persons with severe dissociative states experience psychiatric care and how psychiatric care staff experience caring for them, all in contribution to knowledge on how to support the recovery of persons with severe dissociative states.

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Data is available upon reasonable request.

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